

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

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Korean Higher Education

Pasadena, California

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SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

I. Prevention

Diseases mentioned:

- Leukemia
- Flesh-eating bacteria

II. Immunization

A. Reasons not to get vaccinated

- Lack of time

B. Reasons to get vaccinated

- To avoid unnecessary suffering

C. Ways parents are reminded of vaccine schedule

- A note from the doctor's office
- Some form of self-reminder
- Some participants suggested a centralized database

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

Positive reactions:

- Some Korean respondents welcomed the idea of a central registry.
- When one respondent called a doctor for an immunization record, he found that the doctor had moved out of state. If there had been a central registry it would have been easy to obtain the record.
- Parents would have more time to tend to emotional needs of first-time students starting school rather than worrying about immunization paperwork.

Negative reactions/concerns

- Respondents indicated a concern about privacy.

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- Korean participants were positive about the type of information to be contained in a registry.
- The respondents liked the idea of including the vaccine manufacturer's name and lot number of the vaccine
- The participants suggested that the name, address, and telephone number of the doctor who administered the vaccination be included in the registry. They said that it would have the following advantages:
- It would be easier for parents to keep track of which doctor gave which vaccine to their child.
- It would make doctors more accountable if there were any problems.

B. Reactions to including home address and phone number

- A few participants were concerned and considered inclusion of this information as an invasion of privacy.
- Most participants agreed that if the registry were to be effective, it would be necessary to have home address and telephone number.
- The registry would not be able to send a reminder note without home addresses.

C. Reactions to including parent or child Social Security number

- There was resistance to including the Social Security number of parents and/or children in the registry.
- Most of these participants felt that the inclusion of Social Security number would open the door to many kinds of abuses.
- Some respondents noted that if somebody knew your name and Social Security number, they could find out practically everything about you.
- A few participants thought that including the Social Security number in the registry was not any different than giving the number to their children's school. These participants felt that such information was almost public already, whether they liked it or not.
- A small number of respondents felt that, although they did not like the idea, it might be necessary to include the child's Social Security number for accurate tracking.

D. Reactions to including healthcare members enrollment (WIC or Medicaid numbers)

- The Korean participants were unanimously opposed to the idea of including healthcare member's enrollment numbers.
- The main reason for the objection was the shame they would feel if it were known that they were recipients of such aid programs.

III. Access

A. Who should have access

- Doctors
- School officials
- Parents
- Researchers

B. Who should not have access

- Law enforcement officials
- Health insurers

C. Reactions to the idea of linking registry by computer to other health information systems

- Most Korean participants reacted negatively to the idea of linking the registry.
- The idea seemed to make them uncomfortable about the whole concept of the registry.
- They were concerned about too many people having easy access to the registry.
- The respondents were particularly opposed to health insurance companies having access to the registry because they thought it would enable insurance companies to use the information in the registry against them in the future.

IV. Consent and Inclusion

A. Reactions to “opting out” option

- The Korean participants had a positive reaction to the “opting out” option.
- This option made them feel that they had a choice of whether or not to participate in the registry program.
- All participants concurred that knowing they had this option made them feel better, although they probably would not use the option.

B. Reactions to “consent” option

- This option was most preferred among the Korean participants.
- The “consent” option made them feel that they would have total control over participation.

- They liked the “consent” option better than the “opting out” option because it gave them an increased feeling of control.

C. Reactions to “automatic” option

- Reaction to the “automatic” option was extremely negative.
- The participants felt that if this option were adopted, parents would have no control over the content of information or who had access to the registry.

SECTION 3: WRAP UP AND CLOSING

I. Most Important benefit(s) of registries

- Help them remember when it is time for their children’s next immunization.
- Keep track of which immunizations their children have had and which ones are due.

II. Greatest concerns/biggest risks

- Abuses or misuses by a criminal-minded person
- Mistakes by people who input data into the registry
- Difficulty in correcting errors in the registry’s records.

III. Influence of healthcare provider in decision to participate in a registry

- All participants said their doctors’ opinion would weigh heavily on the decision-making when it came to participation in the registry.
- Most participants said they would probably follow their doctor’s recommendation without thinking much about the registry.
- A few participants said they would do some research on the topic, consider both their research results and their doctor’s opinion, then make their own decision.

IV. Suggestion/comments to people who are responsible for how system works

I would want those people who run the registry system to make sure that they protect the individual’s privacy by not releasing the personal information without the consent or approval from the individuals.

The system should be secure, but convenient to people who register. The most important thing is that priority goes to the parent. Government or any law enforcement agency should not be involved in any situation before human rights (are considered).

Just make sure to put in the correct information. Make sure the system is installed for the health of the community and not for other reasons. Make sure that corrections to information entered by mistake are hassle-free. The (registry) system shouldn’t be mandatory by law without any options.

Make sure the objectives of the registry are clearly spelled out. Make sure that policies about access to data and security are clearly defined.

I think the registry is a very good idea and would be beneficial for keeping track of immunizations, but I wouldn't like the idea if California adopted the law that doesn't have any options.

As long as the parents have the option to participate or not, this would be important to the general public.

Let this program be for all children. Allow parents to have the option about their children's information being in the registry or not. Make sure the information is entered correctly.